



# Still Talking

Dedicated to the welfare of Laryngectomees



All Correspondence to: The Secretary, Laryngectomee Association of N.S.W 39/122 Saunders Steet  
Pymont 2009. Ph. 02 95719220. Mob. 0437 378747 Email:admin@stilltalking.org

No 189 The Laryngectomee Association of N.S.W. August 08

## OFFICE BEARERS 2008

### **PRESIDENT:** Brian Gardner

4 Merelyn Road. Belrose 2085  
02 9452- 2858

### **VICE PRESIDENT:** Russell Green

17/765 Princes Hwy. Blakehurst 2221 Ph.95473669

### **VICE PRESIDENT (2)** Peter M<sup>c</sup>Gregor

21/39 Cook Rd, Centennial Park 2021  
02 93317440 0419 4213214

**SECRETARY** Colin Bolton, 39/122 Saunders Street. Pymont  
2009. 02 95719220 .0437 378747

Email admin@stilltalking.org

### **TREASURER / WELFARE OFFICER:**

Carol Gardner: P.O Box 380 Belrose 2085 NSW  
Fax & Phone 02 9451 7926. Email lansw@bigpond.com

**MINUTE SECRETARY:** Mary Halliburton, 94 Carmen Drive Car-  
lingford 2118

**SPEECH AIDS COORDINATOR:** John Chaloner PO Box 31 Sum-  
mer Hill 2130. 02 9799-1154

**NEWS EDITOR** Colin Bolton 39/122 Saunders St  
PYRMONT 2009 02 95719220 Mob 0437 378747

Email: admin@stilltalking.org

**ASSISTANT WELFARE OFFICER & Hospital packs.** Bruce  
Hodges 31 Clack Rd Chester Hill 2162 0404 400 842

## WHO TO CONTACT

**BLOM SINGER SUPPLIES:-** David Smith. 27 Bellevue Pde  
North Curl Curl 2099. Ph 02 9939-1539 Ask for David  
personally

### **SPEECH AIDS, BATTERIES PARTS, ADVICE ON REPAIRS**

John Chaloner PO Box 31 Summer Hill. 2130  
Ph 02 9799-1154

### **SHOWER SHIELDS, STOMA COVER MATERIAL AND WEL-**

**FARE MATTERS.** Carol Gardner, P.O Box 380 Belrose  
2085 NSW Fax & Phone 02 9451 7926

### **ACCOMMODATION ASSISTANCE WHEN NEEDING OUT**

**PATIENT TREATMENT AND AWAY FROM HOME:-** Can-  
cer Council of NSW 153 Dowling St WOOLLOOMOOLOO  
2011 (PO BOX 572 KINGS CROSS 1340) Ph 02 9334-  
1900 Fax 02 9357-2676 Or contact social worker at the  
hospital you will be attending

## IMPORTANT

It is becoming or should I say continuing to be difficult to fulfil my duties as secretary in the way of organising any-thing. Despite there being three means of contact shown on the front page of the newsletter members are still continuing to give information I have requested and need to know to a third party. For example volunteers for visitor training, names for the cruise etc. etc.

Preparing a newsletter and attending to secretarial duties is a time consuming job and it is being made more difficult by members not sending information to the right place.

I am sure Brian & Carol are delighted to have a chat with members but both them have enough to do in their own portfolios without having to relay messages to me.

To this end there is a form asking for the names of volun-  
teers for visitor training please ensure it is filled in correctly. It is not a scrap of use to me getting a message second hand that Joe Blow from whoop whoop has got 10 names'

Your assistance in this regard will really be ap-  
preciated

*Colin Bolton*



## MONTHLY MEETINGS

**N.S.W Association** 3rd Wednesday of month Uniting Church  
Hall Carrington Avenue. Strathfield at 11am **NEW ENGLAND:**  
Meets at 2pm 1stWed. Feb. Apr. June. Aug. Oct. Dec. 2pm  
Conference Room. Rehab Unit Tamworth Base Hosp. 02  
6767

**NEW ENGLAND:** Meets at 2pm 1stWed. Feb. Apr. June.  
Aug. Oct. Dec. 2pm Conference Room. Rehab Unit  
Tamworth Base Hosp. 02 6767 8377 8377

**NEWCASTLE:** 3<sup>rd</sup> Tues. Monthly Mayfield Bowling Club. Ingall  
St. Mayfield. Contact John Lovett 02 4954 8308

**NORTHERN RIVERS:** 4 times annually at rotating venues  
67678377 Contact Speech Pathology Lismore Base  
Hospital

**ALBURY:** Contact Ph. 02 63232011 extn. 323

**CANBERRA:** 1<sup>st</sup> Thu. at 11am. Mar. June. Sep. Dec. Canberra  
Hospital

**SOUTHERN DISTRICTS:** 4th Wed. 11am. Thomas Rachael  
Moore Education Centre. Liverpool Hospital. Ph.02  
96076708 Contact Pres. Richard Patman 9607 6708

**MID NORTH COAST** Port Macquarie Community Health Cen-  
tre. Feb. May. Aug. Nov Contact Craig Suosaari 02 65882823

**CENTRAL COAST** Meet at Central Coast Leagues Club. Co-  
ordinator(s) Vicky Kelly (S.P.) and Ann Moloney (Gosford  
Hospital ) assisted by Bill Byfield 0402 045048

## Should I Plant Annuals Or Perennials?

I talk funny, well different, that is I communicate with an electronic device called a Servox, as I lost my vocal chords to throat cancer back in 2000. I've gone 3 rounds with throat cancer, first time I was scared to death, second time I lost my vocal chords and hence my natural voice and the third time it nearly killed me. After I lost my voice I took early retirement. I was a salesman; I decided that the market for salesman that couldn't talk was small to say the least and would only get smaller... So what else could I do? I started gardening!!!!.....And boy my life ain't been the same since, I thought losing my ability to talk was a life changer, hey gardening is even more so but in a good way.

When you've had cancer you're always worried it's coming back or has it already come back and I don't know it, all natural responses to having had the disease. Will I still be alive this time next year? I had thoughts like that a good bit of the time, tried not to let on to my loved ones but hey I was scared. And then it happened, not all at once but slowly slowly. I kinda got involved with gardening through the back door so to speak. I had a friend who fed birds on their back patio and raccoons came there too and one evening the birds and the raccoons really put on a show and I was hooked, hooked line and sinker. I was going to feed me some wild birds and have wildlife come to my yard to visit me (as I interpreted it. Why I'd have company all the time, birds, squirrels, coons, hey who or whatever wanted some food and water....And I'd watch them every day and evening as I sat out there while reading or listening to the radio. And then I started reading books about feeding birds and read about this other foreign thing I'd never heard of before, 'gardening for birds'.....Gardening for birds?.....What the heck is that?.....Well 3 or 4 hundred or so perennials, annuals, shrubs, roses, vines later, I know what gardening for birds is all about.

Oh back to that other thing, cancer and my doctor....Well I'm tooling along again in life going to every nursery I can find without a GPS in the car, bought every plant that would even remotely provide food for birds and critters, bought so many kinds of bird feeders my wife threatened to leave me if I bought another one, and bird seed, good lord I went through 200 lbs. a month in bird seed like it wasn't nothing. And not regular black oilers like I feed them now but hulled sunflower seeds, the kind they don't even have to crack to eat, the filet mignon of bird seed.....and then low and behold on one of the checkups come to find out I'd had a reoccurrence of cancer, in my case about as close a thing to a death sentence as you'd get with the kind of

cancer I had and the stage etc.

Well I might be getting ahead of myself here, you see I'd been immersed in the world of plants by now for several years and all I looked forward to was seeing them little perennials poke their little heads out of the ground about February, March or so.....I got to thinking about them plants coming back instead of me dying this week or next month or next year, I just about forgot about me and mostly thought about the plants, the flowers, the fragrance of the flowers, the bird's songs, the flittering movement of birds among the flower beds of our yard.....Heck I'd about plumb forgot about cancer....I wasn't going to die, heck I needed to be here to mulch them coneflowers next year, I mean who's going to weed?....Hey I'm going to be here, I got a reason to be here.....One that's not so much about me but about something else.....No doubt about it boys and girls, gardening gives you a reason to look forward to next year and the next and the next without just the fact that "hey I want to be here and don't want to die", which is a reasonable expectation I guess but not completely satisfying in certain respects.....

Oh back to that other thing, cancer and my doctor.....So I'm sitting in his office and he comes in with his surgical nurse and she grabs my hand tenderly and squeezed it like I might die while I'm sitting there in the chair, right away I know the news ain't good and it ain't....most folks in my situation now have a year maybe, probably less but before he has time to tell me anything substantively about what's going on with me I just ask him one question, "Hey doc, give it to me straight, should I plant annuals this year or perennials?" Well I kinda had a goofy grin on my face that I have when I said it and I looked at him and he looked at me and the surgical nurse looked at me and they both looked at each other and then we all burst out laughing at the same time.....That was 8 years ago, I've been growing perennials all these years and I'm still here, you see I've got to be.....I mean who's going to mulch the coneflowers....Who's going to weed? And every time I go for my yearly check-up I ask the Doc the same old question after he checks me out, "Do I plant perennials or annuals this year Doc?" and then we all burst out laughing.....

One caveat, some folks aren't as lucky as I've been so far, they're situation is grave and the humour I implied in my own situation in no way should belittle the fight these folks have on their hands even as we speak. I wish them all well.

*Paul from Alabama*

*Always borrow money from a pessimist; he doesn't expect to be paid back."*

## Stomach Gas and Acid Reflux in Laryngectomees by Carla DeLassus Gress, ScD

Two conditions which may develop or worsen following the removal of the larynx are increased stomach gas, which can produce uncomfortable pressure and belching; and an increase in stomach acid reflux, which causes the sensation of "heartburn" or acid taste, and may be severe enough to require medical attention. Patients who are fitted with the TEP prosthesis often develop more problems with stomach gas than those who use the artificial larynx for several reasons:

If you are able to look into the opening of the prosthesis while it is in place, sometimes you can see the valve opening inadvertently during quiet breathing. You may also be able to hear a "click" with each breath when the prosthesis valve opens and shuts. Small amounts of air may be entering the oesophagus with each breath and move downward into the stomach, coming back up later as a belch. The solution to this problem is to go to a higher resistance prosthesis that isn't as susceptible to the changing air pressures.

Because of design differences, the Provox prosthesis does not cause this problem to the same degree as the standard InHealth and Bivona low pressure/low resistance prosthesis and the InHealth Indwelling devices. A duckbill style prosthesis will frequently correct the problem, but the increased resistance of this design can be too great to get a very good voice for some individuals. The 20 French duckbill made by Bivona can in some instances provide a good balance, offering extra airflow for speech because of the larger diameter, but increased resistance of the valve to prevent inadvertent opening during quiet breathing. So, one approach to reducing air moving down into the stomach of laryngectomees who use the TEP prosthesis is changing the type of prosthesis.

Another problem that can cause stomach gas is related to the surgery itself and how the throat was reconstructed after the larynx was removed. Prior to surgery, there is a more or less concentric valve (sphincter) at the junction of the lower pharynx with the oesophagus that helps to keep the entrance of the oesophagus closed. The sphincter relaxes during the swallow to open the esophageus for the passage of food.

The fact that it is ordinarily closed helps prevent stomach acid from gurgling back up into the oesophagus and throat. If the surgery left this area without much of a protective sphincter then the Laryngectomee may not only suffer from acid gurgling back up into the oesophagus and throat (known as "gastroesophageal reflux disease" or GERD), but also swallow a considerable amount of air. Try eating slowly.

The recommendations for diet modification, head of the bed elevation, etc., can alleviate mild gastric re-

flux. A chronic or severe acid reflux condition requires medications (prescription brand names include Prilosec, Propulsid, Prevacid) for effective control.

An additional problem can be related to almost the opposite extreme, where the reconstructed throat offers too much resistance to the air column moving upwards as it exits the prosthesis for speech production. As a consequence of the operation, scar tissue formation, or radiation, the pharynx or upper oesophagus can be too narrow or constricted, in some cases to the extent that solid food is not easily swallowed.

In some instances the muscles have too much tone (rigidity, tightness, or "hypertonicity"), or go into spasm (cramping). If there is increased tone or spasm, the voice is strained and requires extra effort, or there may be intermittent breaks in the voice where no sound comes out at all. As the air exits the prosthesis into the pharyngoesophagus, it can't easily exit upwards through the mouth (because of the narrowed area or the hypertonicity) and instead moves down to the stomach. If the patient is pushing to make the TEP speech louder, it can exacerbate the problem. For this reason it is important to try to speak effortlessly and use gentle pressure of the finger for stoma occlusion. The pressure for occlusion should eliminate stoma air leakage around your finger or heat-and-moisture exchange device (InHealth Humidifier, Provox stomafilter, StomVent), but not so tight that the entrance to the prosthesis is blocked or that the esophagus is kinked.

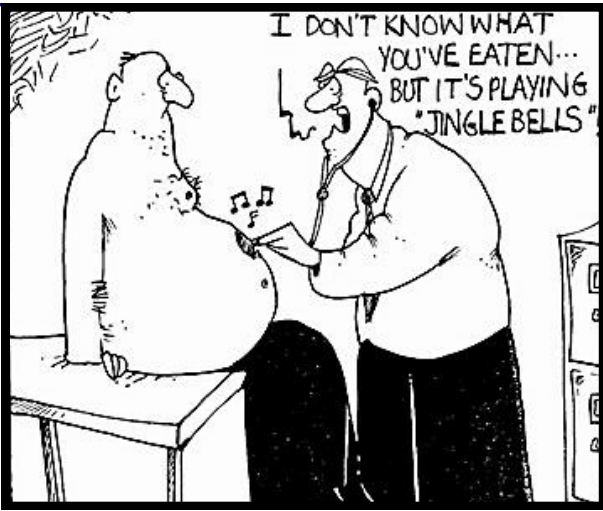
Determining the cause of the problem often takes some detective work. The sound of the voice can give some clues. If the voice is weak and breathy, almost a whisper, it may be related to a "loose throat" But if the voice sounds tight or strained or high pitched, it may be due to a "tight throat" . Laryngectomees who are in the beginning stages of learning oesophageal speech may also experience excess stomach gas and frequent belching as they learn to trap air and release it with the muscles of the throat. This is particularly true if the Laryngectomee develops a "double pump" to initiate the intake of air into the oesophagus. As speech proficiency develops, this problem decreases significantly.

While excessive stomach gas and acid reflux are not uncommon conditions for many Laryngectomees, help in addressing these problems is available from your physician and speech/language pathologist.

\*\*\*\*\*

*I hope that while so many people are out smelling the flowers, someone is taking the time to plant some. - Herbert Rappaport*

*I believe that every right implies a responsibility, every opportunity an obligation; every possession, a duty. - John D. Rockefeller, Jr.*



### What's in a name?

A lawyer named Strange died, and his friend asked the tombstone maker to inscribe on his tombstone, "Here lies Strange, an honest man, and a lawyer."

The inscriber insisted that such an inscription would be confusing, for passers-by would tend to think that three men were buried under the stone. However he suggested an alternative. He would inscribe, "Here lies a man who was both honest and a lawyer."

"That way, whenever anyone walked by the tombstone and read it, they would be certain to remark, 'That's Strange.'

### Panic stations

Bit of a panic on the home front last week. I was nebulising when suddenly I went into a really bad coughing fit and was struggling to breathe. I staggered into the bathroom ready to signal Wyn to phone an ambulance. In the bathroom I saw I had blood coming from my stoma!

I could only think that a foreign object had got down there but could not think what— I always wear a cover and had done nothing untoward. (or so I thought)



*Don't worry about tomorrow*

**After all today is the tomorrow you worried about yesterday**

Next Meeting:  
Wednesday 20th  
August at the  
Uniting Church  
HalCarrington Avenue. Strathfield.  
From 11am Light lunch afterwards



I had enough sense to lie face down on the bed cross wise with my head almost touching the floor while Wyn gave me a few hearty slaps on the back.

Suddenly midst a coughing fit, things eased and looking down I saw I had coughed up the end of a Ventolin capsule that somehow had got into my nebulisor mask and which I had inhaled. Why am I telling you this? We hear of (and see) people who won't wear a cover. This poignant episode reminded me always to wear one and what the consequences of getting a foreign object into the stoma can do

### VISITOR TRAINING

A visitor training day has now been organised for the 24th October at St, Vincent's Hospital Sydney. Times to be announced later. . The association has agreed to pay overnight accommodation costs for country members attending. Please complete the form included in the newsletter.

A reminder that visitor training should not be done without the appropriate training

### A ANNIVERSARY CRUISE

There are still places available on the cruise, please complete the form included in newsletter. Members, their carers , spouses and partners are free as are health professionals. You may bring guests at a subsidised charge of \$30

I am looking for a few anecdotes from the past for the anniversary editon, if you can help please do so. Also wondering who is our longest surviving Larry?

**The August meeting will be special** so please try to make it t.....o help make organising anything of this nature worth while. The last one was a little embarrassing with so few members attending despite what was an interesting and important topic.

Rachelle Robinson, Speech Pathologist at Prince of Wales Hospital, will attend the meeting. She has recently returned from a 9 week training sabbatical tour of UK, America and Netherlands, including meeting with Dr.Blom. She will bring us up to date with the latest developments, and hopefully a lot of hints and tips.



Sponsors of "Still Talking"  
www.mainmed.com.au  
1300 005279  
Importers of Blom Singer

## MINUTES OF MEETING HELD 16TH JULY 2008

### PRESENT

Brian & Carol Gardner. Colin & Wyn Bolton. Mary Halliburton. Robyn Franks. Michel Heapy. Jan Heapy Noel Gilder

### APOLOGIES

Lilah Walton. Pat Lamont. Ray Chappelow. Russell Green. Bruce Hodges Pat Dawson

**FINANCE** A report was given by Robin Franks the association's financial advisor and it was resolved

### **Treasurer's Report 16.07.08**

<b>Adelaide Bank</b>		<b>Commonwealth Bank</b>		
Opening Balance	\$9,777.00	<b>Income</b>	<b>Expenditure</b>	
<b>Income</b>	\$78.00	Opening Balance	\$6,907.00	
		Cancer council	\$127.00	
		Sales	\$497.00	
		Membership fees	\$37.00	
		Cruise Rcpts	\$30.00	
<b>Totals</b>	<b>\$9,855.00</b>	<b>Total</b>	<b>\$7,598.00</b>	
			<b>Total</b>	<b>\$599.00</b>
		<b>Balance of Account</b>	<b>\$6,999.00</b>	
<b>Balance of account</b>	<b>\$9,605.00</b>			
Scandia Balance	509,173.50			

Carol Gardner Treasurer

P Mc.Gregor/Noel Gildear that a finance committee comprising of Brian Gardner Colin Bolton Carol Gardnet Noel Gilder & Peter Mc.Gregor meet to consider our different option and report back—meeting date and place to be arranged by President

Resolved Peter Mc.Gregor/Noel Gilder The report be received.

### SECRETARY'S REPORT

Correspondence from Cancer Council re support groups. Noted the omission of Head and Neck cancer from the support groups. We now have around 20 names for visitor training. And around 45 for the cruise plus around 20 health profession I am trying to get information from other associations regarding anti smoking programmes for schools. Reported on difficulty of trying to get members to send information to the right place when requested. Advise Rachelle Simpson speech pathologist at P of W will give a talk on her 9 weeks recent sabbatical study tour of the UK. America & Netherlands and her meeting with Dr. Blom

### WELFARE REPORT

Winter has taken its toll with many members not well with consequent chills and colds—**DON'T FORGET TO COVER UP!** (This was evident at the July meeting the worst attendance I have seen: Editor)

#### **New members:**

Mustafa Mujedinovic Greenacre. Joe Mayzem of Kahiba. Djordje Petkovic of Cabramatta. Vladimir Bak of Mt.Druitt. John Rope of Watanobbi. Michael Duran of Logan Qld. Cate Durney Baulkham Hills.

**Vale:** William Peter Iles of Mt. Pritchard. Anthony Delaney Miranda.

There being no further business the meeting closed at 12:30 pm and adjourned for lunch .

## Laryngectomy Hospital Visitor Training

A training course is to be held at St. Vincent's on Wednesday 24th October time to be announced. Overnight accommodation will be paid for by the Association for country members. Laryngectomy spouses are invited to attend as of course they are an integral part of this programme. Please ensure that you enter details as requested and post to

**The Secretary. L.A.N.S.W 39/122 Saunders Street. Pyrmont 2009**

Name of Laryngectomy.....Name of Spouse if attending.....

Postal Address.....Post Code.....

Contact number(s).....(essential)

I do / do not require accommodation.....for .....people

If single are you willing to share? Yes/No

You may leave a group contact number BUT you will not be registered as a group without individual names and contact numbers.



## Anniversary Cruise 17th September 08

There is still time and room for more to join us on this special day. Names to:

**The Secretary L.A.N.S.W 39/122 Saunders Street. Pyrmont 2009**

Member.....Spouse, partner, carer.....

No charge for any of the above

Guest(s) .....Please enclose payment of \$30 for each guest

Health professionals..... No charge

The cruise will depart at

11am from The Meadowbank Wharf.

11:40 from Lillyfield

12:10 from Circular Quay—opposite the museum of modern art